BC Ministry of Health Services

Choice in Supports for Independent Living (CSIL) Program Review

Synthesis Report

November 2008

BRITISH COLUMBIA

The Best Place on Earth

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for

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1. Introduction

One component of the home support program in British Columbia (BC) is a self-managed care option called *Choice in Supports for Independent Living* (CSIL). Just 2% of BC's almost 31,000 home support clients have opted for self-managed care but the CSIL program is widely acknowledged as valuable and successful. Participation in the program has grown annually since its establishment in the 1990's and social and demographic trends suggest interest will continue to grow. People are, in general, taking an increasing role in managing their utilization of health and health-related services. At the same time a growing number of people are living at home with chronic illness and/or disabilities and in need of home support and similar services.

There are inherent tensions in self managed care programs – perhaps especially in those that are clearly successful. Policy makers at the government and health authority level struggle to balance competing resource demands, and to ensure programs remain cost-effective, flexible and equitable, while satisfying accountability standards which are often externally imposed. Clients, who understand best the benefits that flow from such programs, seek to maximize their independence and, quite reasonably, are highly motivated to see such programs expanded or enhanced.

It follows that there is a need to periodically review programs such as CSIL. Program reviews provide an essential opportunity to confirm the program remains responsive to client needs, that policy and operational frameworks remain relevant and are being complied with and to clarify, if not align, stakeholder expectations.

A number of relatively independent initiatives have generated reports or working papers regarding CSIL over the past couple of years. The purpose of this report is to synthesize the results of the diverse working papers and reports emanating from the various independent review efforts. It is hoped that by creating an integrated list of areas for action this report will provide a foundation for prioritizing, planning and initiating necessary changes to the CSIL program.

2. Recent CSIL Reviews

The BC Ministry of Health Services (MoHS) initiated a review of the CSIL program in 2006. The review was linked to a need to re-examine public policy related to the payment of family members as caregivers and to understand fully the operational context associated with the policy issue. An extensive consultation process was undertaken utilizing interviews, focus groups and a

questionnaire distributed to almost 500 CSIL clients. While background papers were generated no final report emerged from the process. In response to the Ministry's review, the British Columbia Paraplegic Association (BCPA) facilitated a dialogue involving more than 250 CSIL clients and focusing on the program's benefits as well as opportunities to make CSIL more responsive. The results of the dialogue were reduced to a written report documenting the views of program participants.[1] As these initiatives were beginning, the Vancouver Island Health Authority (VIHA) was in the midst of a regional review of CSIL which also included stakeholder consultation of unspecified scope.[2] The VIHA review took six months to complete and was undertaken in response to perceived inequities in the delivery of CSIL.

3. Developing the Synthesis Report

Typically the development of a synthesis report relies on the application of a common analytic framework to multiple qualitative or quantitative data sources. In the case of qualitative reports such as program reviews, some form of thematic analysis is common with the frequency of themes indicating the relative priority of an issue. The various CSIL review documents diverge greatly in perspective (i.e., client, Health Authority etc), data collection methods and, especially, presentation. This divergence makes it difficult to track themes, which in turn makes it difficult to assess the relative priority stakeholders attach to issues; only two sources come close to identifying priorities and in both instances the lists are brief relative to the range of opportunities or action areas identified.

All of the source materials document in their own unique fashion CSIL strengths and a range of opportunities for change. Ultimately the synthesis is built around a relatively simple presentation of the strengths and opportunities identified in the various reviews. The order in which material is presented is not intended to suggest priority and no discussion of proposed responses to identified opportunities is undertaken.

Prior to discussing the findings emanating from the various reviews it is important to place CSIL in context.

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[1] British Columbia Paraplegic Association. *Employers Review of the CSIL Program: A Compilation.* 2006.

[2] Vancouver Island Health Authority. *Choice in Supports for Independent Living: A Program Review and A New Service Delivery Model.* September, 2006.

4. The Current Policy Framework

Like all programs CSIL operates within the bounds of a policy framework that at once establishes and shapes the program while defining, more or less clearly, its limits. Understanding the relevant policy framework is important to any program review as it provides contextual information important to assessing or categorizing issues and potential actions emerging from the review. More specifically, understanding the policy framework permits stakeholders to identify issues and actions that may lie outside the policy framework governing a program and may therefore be outside the scope of the review and/or necessitate involving different decision making levels to accomplish change.

The policy framework governing CSIL requires Health Authorities (HA) to fund self-managed home support services for eligible clients who require daily personal assistance. Eligible clients are those who have the ability to direct all aspects of their care or have a client support group to do so. CSIL clients or the client support group receive funds directly for the purchase of home support services. They assume full responsibility for the management, co-ordination, and financial accountability of their services including recruiting, hiring, training, scheduling and supervising their home support worker.[3] Clients thus assume the role of an employer with all of the associated obligations. CSIL clients are frequently referred to as CSIL employers.

Home support services, including those delivered through the CSIL program, are intended to:

- Assist clients to live in their own homes as long as it is practical and in the best interests of the client and their family;
- Supplement but not replace the care provided by families, other unpaid caregivers and communities;
- Promote the independence and well-being of clients, their families and other unpaid caregivers; and,
- Provide respite care to the family member or other unpaid caregiver ordinarily caring for the person in the person's home.[4]

Health authorities have discretion in establishing policy respecting the authorization of home support services provided they are consistent with the following requirements:

- Service authorization is to be based on assessment of client health, functional status and availability of support;
- Priority is given to clients with the greatest need or those living at greatest risk;

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[3] BC Ministry of Health Services. Home & Community Care Policy Manual (5.A.4). April 2007.
[4] BC Ministry of Health Services. Home & Community Care Policy Manual (5.A.1). April 2007.

- Service cannot be denied or discontinued where this action alone would result in hospitalization or residential care placement;
- No client can be denied service solely on the basis of the cost of the service required or the fact the client is transferring from another HA.[5]

Two substantive policy changes have occurred since the MoHS launched its review of CSIL in 2006. The policy related to payment of family members who provide home support to relatives who are CSIL clients was amended in mid-2007 to be more permissive. More recently, the MoHS decided to extend the $25,000 earned income deduction used in rate setting and the $300 monthly cap on home support fees, to clients aged 65 or older who have earned income as well as to couples where the client has no earned income but the spouse does; these changes will result in a significant reduction in user fees for several hundred home support clients.

As is typical, the policy framework governing CSIL is both directive and permissive. This combination of characteristics provides for flexibility but also gives rise to variation in practice, a pattern evident in the CSIL reviews.

5. Program Size, Growth & Client Characteristics

The table below presents information concerning the size and growth of the CSIL program.[6]

	Client Count			Hours of Service		
HA	2001/2002	2006/2007	Change	2001/2002	2006/2007	Change
Interior	97	127	31%	169,187	321,793	90%
Fraser	119	166	39%	243,963	372,767	53%
Vancouver	160	179	12%	310,405	371,347	20%
Vancouver Island	134	181	35%	222,012	319,790	44%
Northern	35	50	43%	49,025	74,273	52%
BC	540	701	30%	994,592	1,459,970	47%

[5] BC Ministry of Health Services. Home & Community Care Policy Manual (5.A.2). April 2007.
[6] BC Ministry of Health Services. Home Support Client Counts & Service Volumes. CERTS 2008-0040.

Despite 30 percent growth in clients and nearly 50 percent growth in hours of service over the five year period ending 2006/2007, the CSIL program is utilized by just 2 percent of home support clients. Clients and case managers alike express concern as to whether CSIL is sufficiently promoted, but it is notable the program has grown while the rest of the home support system has not; non-CSIL home support client counts and service hours declined by 13 percent and 4 percent respectively over the same five year time period. Home support expenditures have increased for both CSIL and non-CSIL clients but the increase has been more dramatic for CSIL clients. CSIL expenditures increased by 47 percent ($24.865M to $36.499M) over the five year period compared to 29 percent ($233.640M to $300.400M) for the balance of the home support program.[7]

CSIL and non-CSIL home support clients differ significantly in terms of the hours of support required, demographics and functional diagnoses. Although CSIL clients represent a small proportion of total home support clients, the CSIL program consumes roughly 17 percent of all home support hours.[8] In 2006/2007 CSIL clients received an average of 5.71 hours of support per day compared to an average of 34 minutes per day for non-CSIL clients.[9] VIHA data suggests CSIL clients tend to be substantially younger (average age 47) and more independent than clients in the conventional home support program (average age 74). The most common functional diagnoses amongst CSIL clients are quadriplegia (58 percent) and paraplegia (14 percent) whereas physical frailty (37 percent) is more common among conventional home care clients.[10]

6. CSIL Strengths

All of the reviews examining the CSIL program emphasize the value of the program and its strengths. The program is described as providing independence, autonomy, flexibility, versatility and control to CSIL clients.

In practical terms, CSIL permits clients to manage resources as they see fit. CSIL clients can schedule supports for when they are most needed. This facilitates participation in activities of the client's choosing by eliminating the constraints associated with being governed by someone

[7] CSIL expenditures calculated by applying a rate of $25/hour to hour's data presented in BC MoHS, Home Support Client Counts & Service Volumes, CERTS 2008-0040. Non-CSIL expenditures calculated as the difference between total Home Support expenditures as reported by HA's in August 2007 and calculated CSIL expenditures.

[8] Calculated for 2006/2007 based on hour's data reported in BC MoHS, Home Support Client Counts & Service Volumes, CERTS 2008-0040.

[9] CSIL and non-CSIL average hours per day calculated (Total Hours/Total Clients/365) based on hour's data reported in BC MoHS, Home Support Client Counts & Service Volumes, CERTS 2008-0040.

[10] Vancouver Island Health Authority. *Choice in Supports for Independent Living: A Program Review and A New Service Delivery Model.* September, 2006. p 17-21.

else's schedule. While this may seem a small benefit it advances the ability of CSIL clients to set goals, to engage life on their own terms - as we all wish too - and to be more involved in their communities.

As employers CSIL clients acquire management and other skills, participate in the workforce and provide work. Being in the position of employer permits CSIL clients to train staff in relation to the client's particular circumstances and may also afford the opportunity to retain staff thus resulting in more consistent care.

From a health system perspective, CSIL may reduce expensive hospitalizations, some of which might be lengthy, and certainly reduces the demand for residential care beds.

7. Action Areas

The source materials consulted for this report identified action areas where change could enhance the CSIL program. The identified opportunities varied in number but were remarkably similar in one respect – most relate to the minutiae of program management. The intent here is not to diminish the importance of the opportunities or the challenge associated with acting upon them. Rather, the intent it is to highlight the positive implications this observation has for the CSIL program. The identified opportunities do not reflect fundamental failings in CSIL but relate primarily to the management of a successful program in a decentralized health system. Acting on the opportunities appears to be a matter of refining the program as opposed to overhauling the program.

Only one of the review documents considered in this report explicitly identified priorities. The BCPA document identified approximately nineteen action areas but highlighted three as being most important. The three included: *assessment tools and allocation of hours; resources to promote CSIL and support CSIL clients;* and, the *hourly rate for support workers.*

The survey of CSIL clients undertaken through the MoHS also provides some insight into priorities as the tabulation of results counted the number of times specific opportunities were mentioned. Three action areas were mentioned repeatedly (representing 83% of comments) including: *allocation of hours and the hourly rate and the impact the latter has on recruiting and retaining staff; payment to family members*; and, *orientation and training for CSIL clients.*

There is clearly some overlap in the listed priorities but they do not capture all of the action areas identified. A more comprehensive summary of action areas is presented briefly below.

7.1 Equity

CSIL clients and HA staff alike identify a need for *common operating procedures* to govern the delivery of the CSIL program across the Province. Amongst CSIL clients there is a feeling that consistency has suffered since regionalization while amongst HA staff there is a sense that clear guidelines are absent. The challenge involves finding a balance between the directive and permissive dimensions of the policy framework governing CSIL. Stakeholders envision a home support program which treats conventional and CSIL clients equitably, is characterized by common guidelines across HA's and retains the flexibility to address the individual needs of clients.

Aspects of the *assessment process, caps on hours of service, portability of benefits*, and *appeal processes* also represent areas for action. CSIL clients believe the assessment process needs to be more transparent, more individualized, less subjective, and less medical in focus. A cap on hours of service is a contentious area. CSIL clients are of the view individual and program caps exist and HA documentation certainly supports the perception. There is also a view that home support caps for non-CSIL clients are playing a role in directing clients to CSIL without ensuring client/program fit. CSIL clients also express concern hours are not allocated to CSIL and non-CSIL clients in a consistent manner; specifically, there is a concern hours allocated to CSIL clients are adjusted downward on the assumption the relationship between purchased hours of care and funded hours is routinely greater than one to one.

Portability of benefits is seen as an area for significant change. It is not possible at present to transfer support hours from one HA to another. A decision to relocate entails terminating an existing agreement and being reassessed in the new HA with uncertain results. CSIL clients envision a seamless program where geographic transitions do not entail anxiety regarding the availability of the program, reapplication to the program or reapproval of hours.

Independent appeal processes, which might mitigate some of these matters, require development in the view of CSIL clients. CSIL clients note they are sometimes told there is no appeal process related to funding or other decisions or, if there is a process, it varies geographically. Appeals are also an internal process rather than one carried out by an independent third party. Minimally, more effective communication regarding existing appeal processes and consistent application of those processes may be warranted.

7.2 Relevance

In addition to issues such as transparency, mentioned above, there are more fundamental concerns regarding assessment processes and/or tools used to determine the allocation of monthly hours. Some CSIL clients are assessed using an assessment process/tool that is viewed as more germane to residential care and out of touch with the lives most CSIL clients seek to live. Stakeholders in general acknowledge the tension that exists for both clients and providers when attempting to use common tools for a client population that encompasses traditional home support clients as well as CSIL clients. From the perspective of CSIL clients, the *assessment tool* should be objective, valid and relevant to the aspirations and expectations of clients who want their supports to enable varied, contributing and independent lifestyles. Assessment processes that reflect scheduled, timed interventions are perceived as the antithesis of independent living.

7.3 Developing Partnerships

As noted previously, many of the action areas identified in recent CSIL reviews relate to management of the program at various levels. These matters are best resolved through shared effort by clients, HA staff and others. CSIL clients see *opportunities for greater involvement of people with disabilities* in decisions impacting the CSIL program. They note people with disabilities were at the table when the program was developed and feel a strong sense of ownership for the program. There is an issue of *communication* that seems evident in many of the areas identified for action. New and/or enhanced partnerships may offer potential to address many communication issues as well.

As home support is intended to supplement care provided by other caregivers, *partnerships with community groups* and others willing to support clients is also viewed by some as offering potential benefit.

7.4 Reducing Barriers to Access

HA staff and CSIL clients share a view that the CSIL program could be accessed by more home support clients. Part of achieving greater use of CSIL involves more *promotion* of the program amongst groups such as seniors but removing barriers to access is also important. CSIL clients feel strongly that *user fees* should be removed for all home support clients. Restrictions related to daily personal care requirements are of concern to CSIL clients as is the manner in which some HA's determine a client's ability to self-manage versus requiring the involvement of a client

support group. Many individuals with disabilities are being encouraged to move to 'assisted living' or 'shared care' housing models. *Attaching support to housing* is viewed by some as decreasing the ability of people with disabilities to live independently as care is tied to place of residence and to the schedule of a caregiver serving multiple clients. This situation might discourage potential clients. CSIL clients believe potential clients should be informed of the range of available alternatives and be free to choose the option or service configuration they prefer.

There also remains a perception that HA's are creating *waitlists* or imposing *qualifying periods* on potential CSIL clients for budgetary and other reasons. CSIL clients are of the view the focus needs to shift from tools such as qualifying periods in favor of initiatives that facilitate client success in their choice of service delivery model. Alternatives to *client support groups* may also have a role to play in enhancing access. CSIL clients feel client support groups are being required in circumstances where they are not necessary and HA staff would like to see the functionality of some client support groups improved.

7.5 Ensuring Success

CSIL and HA staff identify a need for *training and support* for both HA staff and CSIL clients to ensure their respective success. CSIL clients speak to the need for orientation and training in regard to CSIL's business processes while HA staff desire an opportunity to network with others involved in administering the CSIL program.

Case management practices and *case load* are also areas where action might promote success. There is some concern that existing case management practices both fail to direct appropriate clients to CSIL and directs inappropriate clients to the program. The latter situation is viewed as arising when complex clients are deemed unsuitable for regular home support and CSIL becomes the default offering. CSIL clients are also of the view that assessment practices should accommodate the working disabled and therefore assessments may need to happen outside work hours.

In terms of case load, HA staff note that case managers can have virtually no experience with CSIL at one extreme to very heavy CSIL case loads at the other extreme. Case loads in general are identified by some stakeholders as an impediment to case managers providing more support or having more ongoing contact with CSIL clients, while CSIL clients note that some form of resource centre for CSIL clients might ease some of the demands on case managers' time.

In addition, a competitive *hourly rate* is viewed by clients as essential to attracting and retaining qualified workers as is the ability to *contract with employees, agencies or other individuals.* Contracting is seen as offering more flexibility in how support is acquired as well as the potential

to retain individuals with special expertise to manage specific aspects of the program (i.e., recruitment services). CSIL clients are very concerned the hourly rate has not kept pace with agency rates. Similarly, they believe provisions related to *retention of surplus* also have a role to play in ensuring success by providing financial flexibility in times of emergency.

Support such as that offered by an accountant is viewed as vital but *resources to pay an accountant* are seen to be an issue. There are also issues related to other allowable expenses with the most contentious one being *advertising allowances*. CSIL clients express concern regarding the impact limits have on the ability to recruit staff while HA staff express concern regarding spending levels. In general, CSIL clients advocate for an approach that emphasizes flexibility in the management of financial resources combined with accountability.

Modified reporting requirements are viewed as contributing to client success by easing the workload requirements associated with CSIL. HA staff identify a need for appropriate infrastructure to monitor financial arrangements while CSIL clients call for greater continuity in terms of their HA contacts for such matters. *Plain language contracts with consistent terms, explicit entry/exit criteria* and *employing family members* are action areas identified by CSIL clients that might also contribute to client success.

8. Conclusion

This report synthesizes the results of recent reviews of the CSIL program. The reviews took similar methodological approaches to their examination of CSIL but their primary perspectives were diverse, representing government, health authorities and CSIL clients. Despite this diversity the initiatives turned up relatively similar areas for action thus providing a rather unique validation of their respective results. Broadly grouped the action areas address the dimensions of equity, relevance, developing partnerships, reducing barriers to access and ensuring success. It now remains to prioritize the action areas, a matter only weakly addressed in the reviews and from there to develop specific responses to address the priorities.

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